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AUTHOR Dufresne, Derrick F.
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ABSTRACT

Historically, in the field of developmental disabilities, the place of residence determines the level of support provided. This has led to a situation in which the more home-like the residence, the less public financial support it receives. The more disabled an individual is and the more difficulties that individual presents, the further he or she is from ever having a place to call home. Severely disabled individuals face difficulties in facilities, such as difficulties in learning when surrounded by others with behavioral problems or intensive needs; the failure to generalize skills; and a reward system which requires individuals who learn and grow to move to other facilities, leaving their neighborhood, friends, and surroundings. The concept of supported housing is an attempt to bring supports needed by an individual to his/her home, equal to the support provided in the traditional continuum of services. Adoption of this concept requires acceptance that supported living is not necessarily cheaper than other forms of residential care. The most fundamental creed upon which supported housing is based is that everyone deserves a home. There is no "readiness" required to live in the community. (JDD)

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NO PLACE LIKE HOME

Derrick F. Dufresne
President
Community Resource Associates
736 Crab Thicket Drive
St. Louis, MO 63131
(314)821-3316

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Be It Ever So Humble, There's No Place Like Home

Nathan and Mila have found a place to call home. In several weeks, Mila will move into a single family home with a friend. Should the landlord ever decide to sell the property Mila and her roommate may have the opportunity to purchase the property. Nathan has moved into an apartment with two roommates in a part of town he likes that is close to shopping, the bus line and recreational opportunities.

There is ~~nothing particularly striking about their~~ stories unless one understands something about the individuals. Mila is blind, deaf and diagnosed as having severe retardation. She was told in April that her institutional placement would terminate at the end of the year because the private institution found her behaviors difficult to manage. Nathan had been referred to many community placement facilities in the State of Missouri only to be told that his behaviors and history were such that he could not be accepted into their programs. For a long time, Nathan and Mila have lived in **facilities**.

Few things are more sacred than one's home. Webster defines "home" as:

> ***The place where a person (or family) lives; one's dwelling place; specifically, a house, apartment, etc., where one lives; a place thought of as home, a place where one likes to be; a restful or congenial place.***

Interestingly enough, Webster does not include in his definition the use of the word, "facility" as a place to call home. Yet many individuals with developmental disabilities do not live in a place they can call "home" unless they live in their parents' home or are very "high functioning" and rent their own apartments.

Many individuals who are severely and profoundly retarded, physically disabled or have intensive support needs live in facilities.

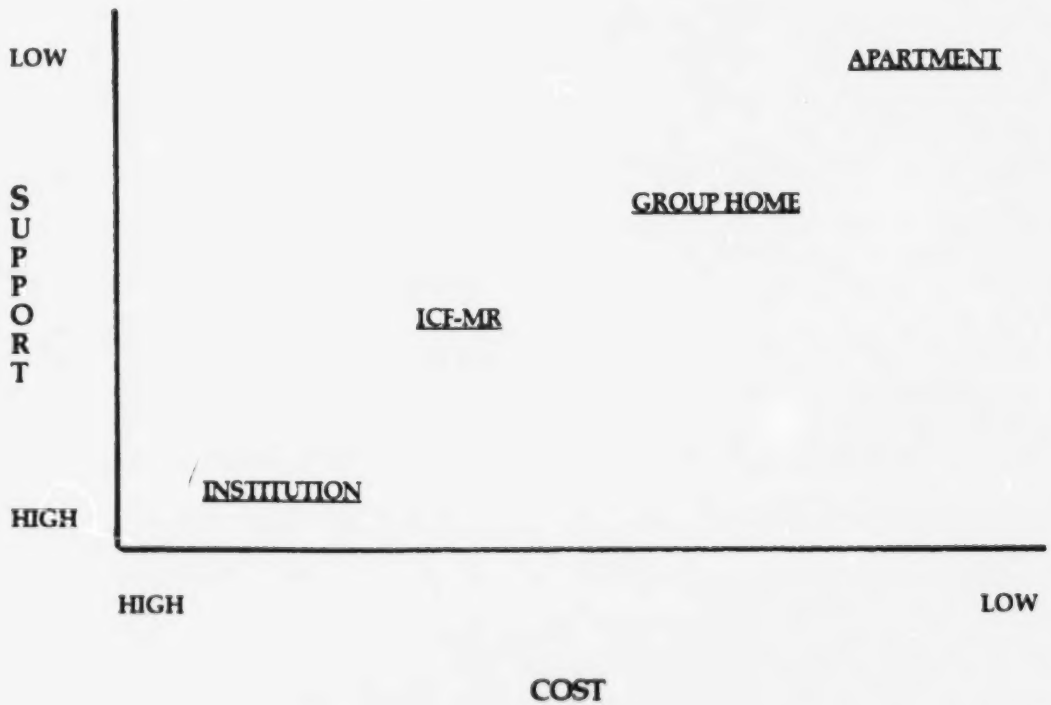
Webster defines "facility" as:

> ***A building, special room, etc. that facilitates or makes possible some activity.***

Notice in the definition of "facility" there is no mention of home nor is there any mention of a place someone would like to be. The definition specifically speaks to the issue of activity.

Historically, in the field of developmental disabilities, where you lived determined the level of support you received. Second, the level of support usually translated into the amount of dollars spent. Therefore, individuals with the greatest needs for support have lived in facilities and individuals requiring the least amount of support have lived in homes. The obvious exception to this is an individual with disabilities who lives with his/her family.

This is best illustrated by the following graph:



I have visited numerous families who are caring for their children at home - children who are on ventilators, certainly medically fragile and, in many cases, physically disabled. These individuals live in homes. If, however, it becomes necessary for an individual to be placed out of his/her natural home, in many cases he/she doesn't move to another home. He/she moves to a facility.

As is readily apparent, historically the greatest degree of support and ~~amount of funds have been expended on individuals~~ living in state institutions. According to research done by David Braddock, et al., The State of the States in Developmental Disabilities, (Paul H. Brooks Publishing Co., 1990), the federal government's contribution to funding for people with developmental disabilities averaged more than 80% spent in large congregate (over 15 people) settings in recent years. **The simple fact is the more the place looks, feels like and is a home, the less we have been willing to spend on it.**

This has set up a caste system of services. People who are most capable, have the most skills and pose the least amount of difficulty get to live in homes. People with special needs, behavioral difficulties or those labeled "medically fragile" are relegated to life in facilities.

This thinking called a "continuum" model is based on technology that is now almost twenty years old. The idea that people need to learn a certain set of skills in one setting to progress to another setting created a series of facilities all of which had a different purpose. Each time a new diagnosis or a group of people in need presents itself, a new facility is developed. The highest goal is independence for the few, the proud and the brave that can wade through the system.

My biggest fear about this type of system is what it means for individuals who need to be "ready" to live in the community. The more

disabled you are, the more skills you lack, or the more difficulties you present, the further you are away from ever having a place to call home.

I have heard comments made about congregate facililties (a redundant term), "She feels like that's her home", or "We even have numbers on the individual units and she has all of her personal belongings and all of her friends live there". I can't help but wonder in those particular situations if a person with disabilities and their families knew that other options existed and that the level of support provided in a home could mirror that provided in a facility, that they would still choose a facility.

What then will replace the continuum? An array of supports can be provided to a person with disabilities, despite past failures or inabilities to "make it" in the community.

Fundamental to this way of thinking is the separation of housing and services (supports). This concept, often called "supported housing", says that no matter where an individual lives supports can be brought to him/her in a home equal to the degree of supports that are provided in the previously defined continuum of services. Therefore, anything that can be provided in a state institution can be provided in a condominium. Anything that can be provided in an ICF-MR can be provided in a duplex. Anything that can be provided in a group home, can be provided in an apartment. This includes the provision of twenty-four hour live-in staffing, visiting nurses, therapies and other interventions that have typically been provided only in facilities.

In order for this philosophy to be implemented, previously held beliefs involving the intermingling of supports and where you live must be re-examined. This includes the reality that while supported living is better, it is not necessarily cheaper. Some individuals will require an

intensity of supports that may meet or exceed the costs of some institutional care.

In supported housing, flexible supports are provided to an individual based not only on strengths and needs but individual wants. Thus, where the individual lives, with whom he/she lives and the configuration of supports are not predetermined. One does not put a spade in the ground, develop a "facility" and then find out who is going to live there. As a matter of fact, in supported housing, the physical housing is one of the last things that is addressed. First and foremost we must have a vision of

the future that encompasses work, home and leisure, but most closely reflects the way individuals without disabilities live.

I am certainly aware of the arguments that start with, "This is great, but it won't work for my son or daughter. They're too disabled." Or, "We tried Judy in the community once and it just didn't work. She simply couldn't make it". It is perfectly understandable why parents and even some providers currently believe that there are certain individuals that could never make it in an apartment, duplex, condominium or small single family home. This belief in many cases is rooted in the continuum which holds that only people who are independent can live in a place called home.

Research and experience in recent years have caused a complete re-examination of the continuum. In applying this to the current system, one can readily see how many individuals in these settings experience difficulties living in facilities the more disabled or needy he/she is. It is easy to understand why difficulties in learning would occur when one is surrounded by others with behavioral difficulties or intensive needs.

Second, many individuals with severe disabilities do not generalize well. Thus, the skills learned in one setting may not transfer to the new setting. Thus, the best attempts of individuals working in congregate settings to teach "readiness" or community living skills may have limited success when these skills are transferred to a real live setting. This leaves behind in many facilities a group called the "residual population" whose needs are so great, they are rarely, if ever, referred for community placement.

Finally, the current continuum of services rewards individuals who learn and grow by having them move to another facility which is a step on the road to independence. When they move, they must leave their neighborhood, friends, and comfortable surroundings. This contrasts with supported living. If the individual's need for live-in support lessens, then the staff, rather than the individual, moves.

The most fundamental creed upon which supported housing is based is that <u>everyone deserves a home</u>. There is no readiness to live in the community.

In separating housing and services (supports), we see exciting options currently being offered throughout the country that involve consumer ownership of housing, parent ownership and private sector involvement in a number of ways. The housing is actually the easier part of the configuration if you are dealing with real estate professionals who understand the importance of using regular housing stock for people with and without disabilities.

Group homes, ICF-MR's and other congregate living settings are an idea whose time has come and gone. As we look to meet the challenge of the 90's and look to the year 2000, our focus should be on finding a place to call home for every individual with disabilities. And when the word "everyone" is used, it includes people on ventilators, people with

severe behavioral difficulties, people without speech., etc. The degree of disability should have no relationship to the right of every person with disabilities to have a place to call home.

Be it ever so humble, there's no place like home!